DOCUMENT RESUME

ED 351 841 EC 301 668

TITLE Congenital Heart Disease: Guidelines of Care for Children with Special Health Care Needs.

INSTITUTION Minnesota State Dept. of Health, Minneapolis. Services for Children with Handicaps.

PUB DATE 90

NOTE 41p.; For related documents, see ED 340 155-156 and EC 301 667.

PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC02 Plus Postage.

DESCRIPTORS Adolescents; Child Development; Children; *Congenital Impairments; Elementary Secondary Education; Family Programs; Guidelines; *Health Needs; *Health Services; *Heart Disorders; *Human Services; Infants; Parent Role; Preschool Education; Resources; Special Health Problems; Youth

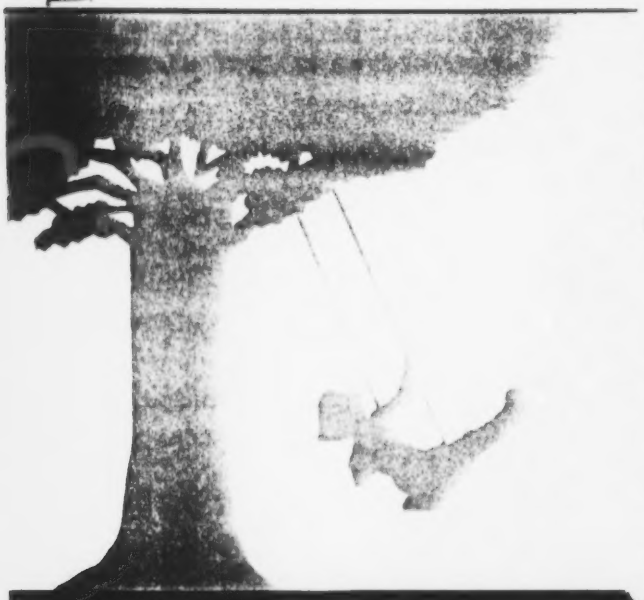
ABSTRACT

These guidelines were written to help families coordinate the health care that may be needed by a child with congenital heart disease. The booklet begins with general information about congenital heart disease. It then discusses the goals of health care, the health care team, the importance of periodic health care, and record keeping procedures. The child's health care needs, development, and educational needs are then examined by age, from birth to age 21. Family support and services are described, including advocacy, human services, schools, family support groups and networks, and recreation. The booklet concludes with a glossary, a list of organizational (primarily in Minnesota) and printed resources for children with congenital heart disease, and a list of more general resources for children with special health care needs. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED251841

Guidelines of Care for Children with Special Health Care Needs



U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it

☐ Minor changes have been made to improve reproduction quality

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

M Wannieger

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

CONGENITAL HEART DISEASE

EC 301668

BEST COPY AVAILABLE

Published by
Minnesota Department of Health
Services for Children with Handicaps (SCH)
717 SE Delaware Street, Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free, voice or TDD)

1990

BOOKLET MAY BE REPRODUCED

Information contained in this booklet is meant to supplement the advice of a physician or other health professional. Ask your physician about your child's specific needs.

Credits

Thank you to the many families, physicians and health professionals who shared their expertise and insight for development of the guidelines. Also, thanks to the members of the Ad Hoc Advisory Task Force for their assistance in planning and developing the guidelines.

Elizabeth Blake
Public Health Nurse Consultant
Project Coordinator

Brenda Carlson
Graphic Artist

Dale Thompson
Manuscript Editor

Carolyn McKay
Pediatrician, Director
Maternal and Child Health

Mary Wanninger
Nursing Director
Project Supervisor

Co-burn J. Porter, MD
Associate Professor of Pediatrics, Pediatric Cardiology, Mayo Clinic

Ad Hoc Advisory Task Force Members

Edroy Anderson
Social Work Consultant, SCH

Maria Anderson
Parent of a Child with Special Needs and Advocate, PACER Center

Adrienne Barnwell
Child Psychologist, Gillette Children's Hospital

Joan Bohmert
Physical Therapist, Anoka-Hennepin Learning Center

Sheila Farnan
Registered Dietitian, Nutrition Consultant, SCH

Chris Gehlsen
Patient Care Coordinator, Prudential Insurance Company

Shirley Kramer
Parent of Two Children with Special Needs

Georgianna Larson
Executive Director, Pathfinder

Lynne Lent
Occupational Therapist, Anoka-Hennepin Learning Center

Barbara Matykiewicz
Maternal-Child Health Coordinator, Ramsey County Public Health

Cyndy Silkworth
School Nurse, White Bear Lake School District

Marsha Zuckerman
Social Worker, University of Minnesota Hospital and Clinics

CONTENTS

Page

Introduction 7

General Information 9

Health Care 13
The Health Care Team 14
Periodic Health Care 15
Record Keeping 17

The Child's Needs 19
Infants and Toddlers — Ages 0 to 2 19
Preschool Children — Ages 3 to 5 21
School-age Children — Ages 6 to 12 22
Adolescents — Ages 13 to 17 24
Young Adults — Ages 18 to 21 25

Family Support and Services 27
Advocacy 27
Schools 27
Human Services 27
Family Support Groups and Networks 28
Recreation 28

Glossary 29

Resources for Children
with Congenital Heart Disease 31
Organizations 31
Books, Pamphlets, and Videos 32
Articles for Health Professionals 32
Specialty Medical Care 33

General Resources for Children
with Special Health Care Needs 35
Organizations 35
Books, Pamphlets, and Videos 41
Health Care Financing 44

5

INTRODUCTION

These guidelines are written for families and health professionals. They can also be used by anyone who cares for a child with congenital heart disease including teachers, school personnel, friends, and relatives. Readers may find different sections of the booklet useful at various times during the child's development.

The primary purpose of the guidelines is to help families coordinate health care that may be needed by a child born with congenital heart disease. This information may help families determine which services are needed for the optimal growth and development of their child. To do this, families need to understand the health care system and how to use it effectively.

Health care services are a resource for families. They provide information and care for children with special health care needs. Families who are actively involved in coordinating their child's care assure their child better health care. This is because informed, involved families can promote communication with and between health professionals. Informed families also understand how the health care plan meets the needs of their child better than anyone else. These parents know when the plan is not working well for their child. They can identify unmet needs or duplication of services. Parents are encouraged to actively participate with health care providers to assure that the child's needs are met.

The challenge to health professionals is to serve families appropriately and effectively by providing **family-centered care.*** This can be accomplished by providing health care within the context of each family's values, ideals, culture, and lifestyle. The family also benefits from **community-based** services, as close to the child's home as possible.

Individual children's needs vary. These guidelines list the most common health care needs for a child with congenital heart disease. ***Ask your doctor how your child's health care needs are different from those listed here.***

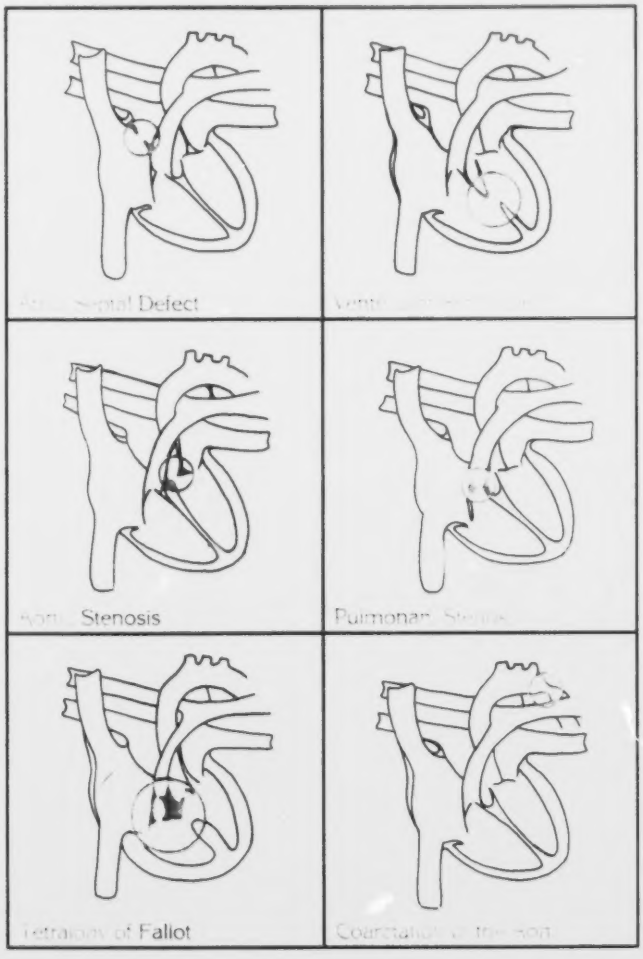
*Words that you see printed in dark type are explained in the glossary that appears later in this booklet. Turn to the glossary whenever you are not sure of the meaning of a word in dark type.

GENERAL INFORMATION

What is congenital heart disease?

Congenital heart disease is a condition where a baby is born with a defect in the structure of the heart, surrounding blood vessels, or both. There are more than 150 different types of congenital heart disease. Some types of heart defects cause obvious problems such as causing the child's skin to look blue. Other heart defects are more difficult to find.

Common Heart Defects

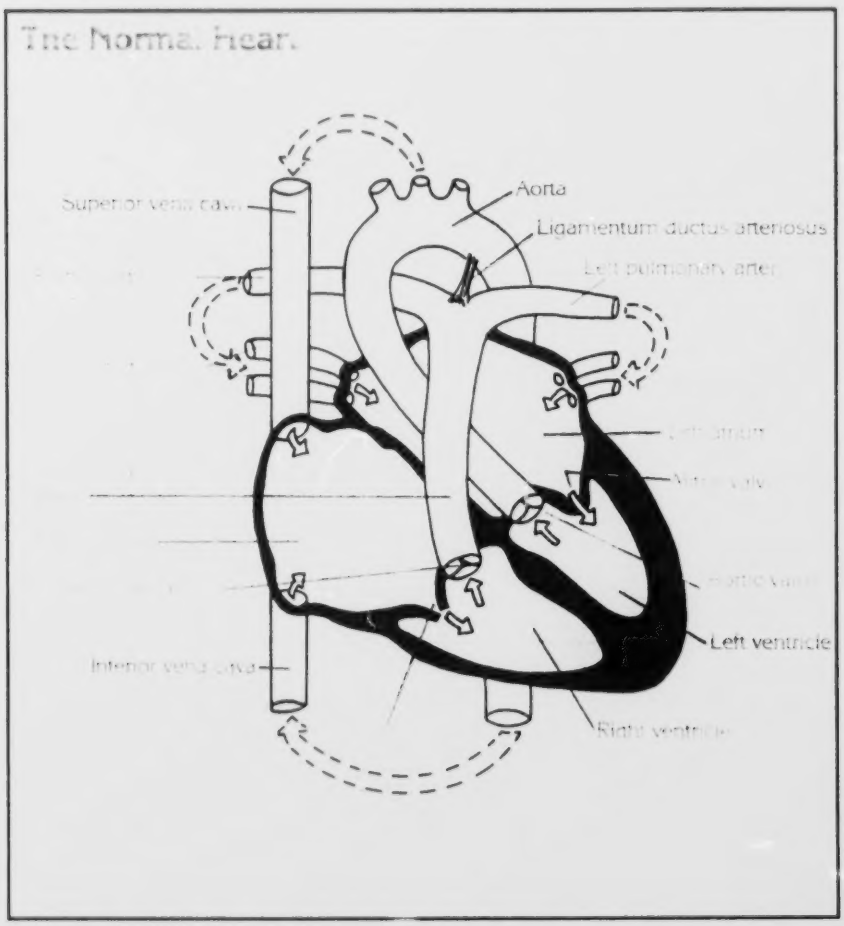


Illustrations copied from the American Heart Association.

BEST COPY AVAILABLE

What causes congenital heart disease?

The baby's heart develops early in pregnancy and begins to take shape in the third week of development. Many heart defects develop when the heart is being formed, early in pregnancy. Some heart defects are caused by heredity. Others are caused at birth when expected changes in blood circulation do not occur. Doctors are usually unable to find a direct cause of congenital heart disease.



Illustrations copied from the American Heart Association.

BEST COPY AVAILABLE

What are the symptoms of congenital heart disease?

Symptoms of congenital heart disease vary depending on the size and type of defect. Most children have no symptoms and grow and exercise normally. Some infants and children with heart problems may tire easily, grow at a slower rate, or have a bluish color to their skin, especially when they cry.

Are some children born with more severe congenital heart disease than others?

Some types of congenital heart defects have more severe symptoms than other types. This often depends on the type and size of the defect. Many heart defects cause no apparent symptoms. Children with mild problems often do not need to have surgery to correct the problem.

HEALTH CARE

Many health care providers use the **Family-Centered Health Care Team** approach to treat a child or youth with congenital heart disease. Using this approach, health professionals and the family decide together which treatments are best for the child. By coordinating and arranging for their child's health care, the family takes an active part in making the health care plan work.

Health professionals vary in their knowledge and experience. When choosing a doctor or other health professional, ask if he or she has had training or experience with congenital heart disease. Also find out if he or she is comfortable treating a child with a heart condition. If not, most professionals will be happy to refer you to someone with more knowledge and experience in treating the condition.

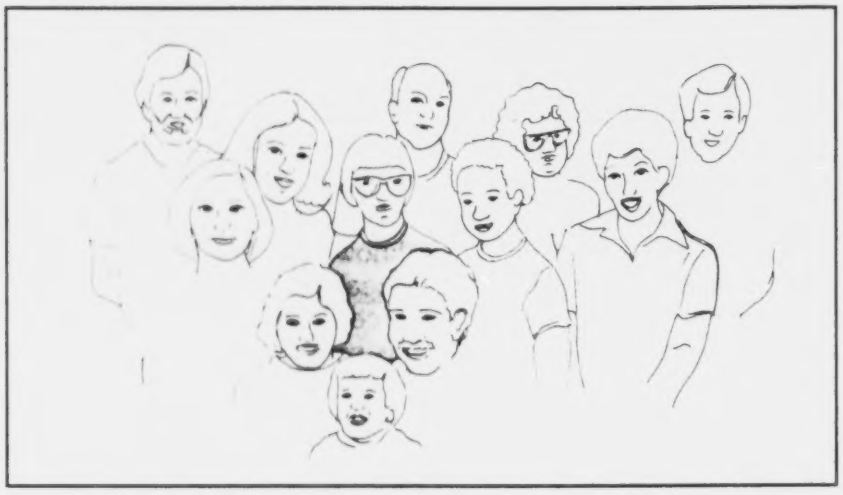
These are the goals of treatment for the child with a congenital heart problem:

- Normal growth and development
- Normal heart function with or without surgical repair
- Normal lifestyle with participation in the usual sports and activities of childhood and adolescence

The **family-centered health care team** can accomplish these goals by taking the following steps:

- Surgically repairing the heart defect if necessary
- Making sure the child gets **prophylactic antibiotics** before dental work or other surgical procedures.
- Monitoring the child's growth and development
- Seeing that the child gets adequate nutrition and activity
- Providing health care team management

The Health Care Team



Members of the Health Care Team for the child or youth with congenital heart disease include:

The Child or Teenager and the family — The most important members of the team!

- Coordinates the child's health care
- Provides the family and child's health history
- Communicates with health professionals about the child's development, treatments, and medications

Pediatrician (children's doctor) **or Family Physician**

- Acts as the primary doctor
- Coordinates medical care between physicians
- Provides well-child care
- Provides sick-child care
- Gives immunizations
- Communicates with the family and other team members

Pediatric Cardiologist (children's heart doctor)

- Diagnoses and treats heart problems in children
- Refers children who need surgery to a cardiac surgeon
- Gives recommendations to the primary doctor

Cardiac Surgeon (heart doctor that does surgery on the heart)

- Treats surgically correctable heart problems

Occupational Therapist*

- Evaluates and treats children with developmental delays, motor problems, and activities of daily living
- Teaches the family about appropriate activities for the child

Registered Nurse, Public Health Nurse, and Nurse Specialist

- Offers information about procedures and care of the child
- Provides preventive and educational counseling
- Helps the family develop a home care plan
- Provides emotional support
- Teaches the family about medications
- The registered nurse also cares for the hospitalized child

Registered Dietitian (nutrition professional)

- Assesses adequacy and quality of diet
- Interprets growth records and certain laboratory tests
- Checks to see if the child's medication and food interact
- Provides preventive and educational counseling
- Develops a nutrition care plan

School Nurse

- Helps the child and the family to coordinate child's health care needs in school and school-related activites
- Helps the child and the family to communicate health information to teachers and other appropriate school personnel
- Helps teachers to provide an appropriate learning environment for the child
- Gives medications in school

Social Worker

- Helps the family learn to balance family life with the child's care
- Helps the family find community resources such as support groups and financial aid

* These people are part of the health care team in cases where the child has additional medical concerns.

Periodic Health Care

Regular health care visits are important to your child's well- being. These visits are necessary to check your child's growth and development as well as his or her congenital heart disease. The schedule of regular visits will vary with the child or adolescent's age. However, all children are individuals and their needs will vary. ***Ask your doctor if your child's health care needs are different from those listed here.***

Primary Physician — Visits to your primary doctor usually follow the schedule for well-child examinations. Usually, this doctor provides care for medical needs not specifically related to the heart condition. These include the following:

- Immunizations
- Height and weight measurement and graphing
- Periodic hearing and vision screening
- Physical examination
- Discussion of child's development since last visit
- Discussion of symptoms since last visit
- Discussion of medications and treatments
- Discussion of your questions and concerns
- Care and treatment of illnesses

Pediatric Cardiologist — Usually the cardiologist will see the child after the primary physician suspects a heart problem. If surgery is recommended, after surgery the cardiologist will do follow-up examinations. The frequency of these examinations varies with each child. Many children with congenital heart disease have follow-up examinations as infrequently as every 1 to 5 years because they are considered healthy. Their only health care need may be to take antibiotics prior to having dental or other surgical procedures. In diagnosing and managing your child's condition, the cardiologist uses various procedures including the following:

Performs tests to diagnose and monitor heart function:

- Asks the family about the child's symptoms
- Performs physical examination to assess the child's overall health
- Performs an **electrocardiogram** (ECG) which traces the heart's electrical activity
- Performs an **echocardiogram** — ultrasound pictures of internal structures of the heart and blood vessels
- Takes an x-ray of the child's chest
- Performs blood tests
- Manages heart problems, which may include making a referral to a surgeon

These symptoms need medical attention between regular visits:

- Increased shortness of breath when the child is active or eating
- Illness, especially with a fever or sore throat
- Dizziness
- Palpitations — the feeling that the heart beat is irregular or fast

These symptoms need *immediate* medical attention:

- High fever
- Shortness of breath that doesn't get better with rest
- Increased **cyanosis** or dusky color of the skin
- Fainting or **syncope**

Record keeping is an important part of coordinating your child's health care. Some parents choose to keep their own records of their child's health care. Other parents prefer to rely on the records health professionals keep. If you choose to keep records, you can use a loose-leaf notebook which can be divided into sections to fit your needs. A calendar can also be adapted to keep records. Section topics may include the following:

- Names, addresses and phone numbers of health team members
- Appointment dates
- Daily care plans — treatments, medications, types of play
- Medication information
- Changes in symptoms
- Records of your child's growth and development
- Immunization records

BEST COPY AVAILABLE

Health Care

- Infants and toddlers with congenital heart disease sometimes must be hospitalized for surgical repair of the heart or blood vessels. During this time it helps the child adjust if parents are present as much as possible for comfort and support. Hospital staff support parents' decisions about how much time they spend with their child. Many hospitals that care for infants have open visiting hours for family members. Infants more than 6 months old and toddlers may be upset when separated from their parents. Children vary in their reaction to separation from parents. Some children quickly become accustomed to new places and people, while others need more reassurance and comfort. When parents are present, they can help prevent unnecessary interruption of the child's sleep. In addition, they can make sure their child's needs are met.

BEST COPY AVAILABLE

- Your child's growth and development should be carefully monitored because some infants tire when feeding and do not eat enough.
- Watch for **respiratory infections.**
- You can ask for assistance in planning to bring your child home. If your child needs home care, hospital staff can help you make arrangements.
- Remember that your child needs the same routine well-baby checkups and immunizations that all children need.

Development

- Children develop faster as infants and toddlers than at any other time in life. Most children with congenital heart disease will grow and develop at a normal rate. However, children with some types of heart problems may lack the energy for moving around and seem to have slowed development. The child's development may improve after the condition is surgically repaired.
- Some infants get tired quickly and do not drink enough milk to grow. Those babies may need to be fed every 2 to 3 hours for a long time if they are not gaining enough weight.
- Provide a safe environment that allows the child to play with the least restriction. Provide toys and activities that are right for your child's age.
- All children are better able to manage life if they feel good about themselves. It is important to begin building self-esteem early by praising your infant or toddler often.
- After the heart is repaired, expect the same behavior from the child with congenital heart disease as from other children. Set appropriate limits on your toddler's behavior. Children who are not feeling well may regress in their behavior at times. They may want parents to do things for them that they previously did themselves. However, these children have the same needs for love and discipline as other children.

School

- Most children with congenital heart disease will not need special education services. Children with delayed development and special health care needs may be eligible for Early Intervention services. This program provides services to children ages 0 to 3 years. In this program, parents are partners in a **multidisciplinary team** that makes

an **Individual Family Service Plan (IFSP)**. You may want to check to see if your child qualifies for services. Contact your local school district to find out how this program works in your area. Ask to speak to the Early Intervention Coordinator.

Day Care

- Most children with congenital heart disease can attend regular day care. They usually do not require different care from other children.

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Children with congenital heart disease need antibiotics prior to having dental care or other surgical procedures. Taking antibiotics before procedures such as cleaning the teeth prevents bacteria from entering the bloodstream and lodging in the heart. If the child does not take antibiotics, there is a possibility that heart valves could be damaged by bacteria from the mouth. Ask your doctor if your child needs this preventive medicine. Health professionals refer to this treatment as **bacterial endocarditis prophylaxis.**

Development

- Provide your child with simple information about congenital heart disease.
- Provide your child with opportunities to do the following:
  - — Play with other children of the same age
  - — Learn to start and complete activities when playing
  - — Have a balance between structured activities and free time to play
  - — Succeed, so your child gains self-confidence
- Children who are not feeling well may regress in their behavior at times. They may want parents to do things for them that they previously did themselves. However, these children have the same needs for love and discipline as other children.

BEST COPY AVAILABLE

School

- Most children with congenital heart disease will not need special education services. Children with delayed development and special health care needs may be eligible for Early Childhood Special Education. In this program, parents are partners in a **multidisciplinary team** that makes an **Individual Educational Plan** for the child. You may want to check to see if your child qualifies for services. Contact your local school district to find out how this program works in your area. Ask to speak to the Early Childhood Special Education Coordinator.
- If your child has any special restrictions on activity, you may discuss them with your child's teachers and the school nurse. See the school information presented in the Family Support and Services section of this booklet.

School-Age Children with Congenital Heart Disease — Ages 6 to 12

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Children of this age are generally very active. If your child has special restrictions on activity, you should ask your doctor for guidance in planning an exercise program. Most children do not need to adjust their activity because of a congenital heart condition.
- Children with congenital heart disease need antibiotics before having dental care or other surgical procedures. Taking antibiotics before procedures such as cleaning the teeth prevents bacteria from entering the bloodstream and lodging in the heart. If your child does not take antibiotics, there is a possibility that heart valves could be damaged by bacteria from the mouth. Ask your doctor if your child needs this preventive medicine. Health professionals refer to this treatment as **bacterial endocarditis prophylaxis.**

Development

- School-age children understand factual information about congenital heart disease. Give them specific information about their condition and explain the reason for scars. Also, encourage them to talk to their doctor about their condition, and to read about it on their own too.
- Allow your child increasing control over diet and medications.
- Encourage your child to be responsible for remembering when to take medications. Mastering self-care skills will give a child self-confidence and a feeling of accomplishment.
- Children who are not feeling well may regress in their behavior at times. They may want parents to do things for them that they previously did themselves. However, these children have the same needs for love and discipline as other children.

School

- Meet with your child's teachers and the school nurse at the beginning of each year. Keep them informed of changes in your child's condition and treatment. For a list of specific topics to discuss with school staff, see the school information presented in the Family Support and Services section of this booklet.
- Children with congenital heart disease usually do not miss more school than their peers. Arrange for homework to be sent home when your child is absent. If your child is absent from school for more than 15 days, request homebound services. A child is also eligible for homebound services sooner than 15 days is he or she is absent frequently or the doctor expects the absence to last more than 15 days.
- Encourage your child to be involved in group activities for children his or her age.

23

Adolescents with Congenital Heart Disease — Ages 13 to 17

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Remind the teenager about the benefits of exercise for developing muscles and increasing endurance.
- Teens with congenital heart disease need antibiotics before having dental care or surgical procedures. Taking antibiotics before procedures such as cleaning the teeth prevents bacteria from entering the bloodstream and lodging in the heart. If antibiotics are not taken, there is a possibility that heart valves could be damaged by bacteria from the mouth. Ask your doctor if your son or daughter needs this preventive medicine.

Development

- Some teens with congenital heart disease may enter puberty later than their peers. Reassure the teen that he or she will mature physically, but possibly at a slower rate than other adolescents.
- Independence is necessary for teenagers to develop responsible behavior. Responsible behavior will usually follow independence, if teenagers understand the benefits and consequences of their actions.
- Teens need to understand if congenital heart disease will affect their sexual and reproductive life. They may need encouragement to ask questions. Discuss any specific concerns with the youth and your doctor. Encourage the youth to discuss concerns privately with the doctor if it is more comfortable for both of you. Inquire about inherited forms of heart disease.
- Smoking is harmful to the health of anyone who smokes, but even more harmful to the teen who has a congenital heart problem.
- Street drug use and alcohol can be especially dangerous to a person with a congenital heart condition. Some drugs can cause an irregular heart beat **(arrhythmia)** or bacteria in the blood **(bacteremia).**
- Peers become increasingly important to teenagers. Teens with high self-esteem can resist peer pressure. They will also be less concerned about being different from their friends.

BEST COPY AVAILABLE

School

- When the youth is absent from school, arrange to receive homework from each of the classes. If their absence is extended, request homebound services.
- Encourage the youth to advocate for him- or herself in school. Teens can keep school staff informed of their needs. At some time during adolescence, most teens will resist advocating for themselves. During this time, other family members may need to keep school staff informed of any health care needs. See the advocacy information presented in the Family Support and Services section of this booklet for more information on advocacy.

Congenital Heart Disease — Ages 18-21

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- If the young adult moves away from home, plan ahead for his or her health care. Some young adults find it helpful to find a doctor in the new area before moving. Your doctor may be able to refer the young person to a specialist in the new area.
- When the young adult moves away from home or gets a job, find out if the current health insurance coverage continues. Some insurance policies will cover young adults only if they attend school as a full-time student. Discuss health insurance needs with your insurance company, social worker, public health nurse, or doctor.

Development

- Young adults focus on life goals, education, and careers at this age. Having a congenital heart defect does not usually limit career possibilities. If they are unsure of their goals, young adults may want to seek assistance in education and career planning.

School

- When they move away to school, young adults may want to plan for regular follow-up visits for cardiac problems. Often students continue to see their cardiologist when they are home on vacation.

BEST COPY AVAILABLE

FAMILY SUPPORT AND SERVICES

Advocacy

Parents of children with special health care needs can be advocates for their child. A big part of advocacy is teaching people about your child's condition and needs. Parents understand their child's needs better than anyone else. This is because parents have a lifelong relationship with their child, while health professionals usually come and go over time.

Another part of advocacy is being persistent in seeking a service or treatment that your child needs. If one person says you do not qualify for the service or the child does not need a treatment, ask another person. Continue to tell health providers about your concerns until you are satisfied with their answers.

Finally, you may need to remind people who are treating your child about treating the whole child. Some health care providers will focus on one goal for your child's treatment, but may forget how that goal affects other areas of your child's life. An example of this is trying to fit treatments into your child's school schedule. You may need to discuss your child's treatment plan with school staff to best meet both needs. Work with health care providers to plan an alternative treatment plan that will work to meet both needs.

Schools

Each year when your child starts school, meet with teachers and the school nurse to discuss the following:

- Your child's knowledge of congenital heart disease
- Medications necessary at school and how responsible your child is for remembering them
- Possible adjustments in physical activity
- What to do in case of absences — send homework home; provide homebound services

Human Services

When a family member has a special health care need, families may feel financially strained. Several health care financial

resources exist for families. Someone at your county social services department may help you find out if you are eligible for any of these. You may also call agencies that offer financial assistance directly and ask them to send you eligibility information. For information about organizations that offer financial assistance, see the material on health care financing in the section on Resources for Children with Special Health Care Needs at the end of this booklet.

Support Groups and Networks

Sometimes it is helpful for parents to talk to other parents of children with congenital heart disease. Other parents who have a child with the same condition can give encouragement and support with an understanding that comes from experience. You can find informal networks of parents through your doctor, pediatric nurse specialist, or social worker. The Association for the Care of Children's Health publishes a *Parent Resource Directory* with names and addresses of families of children with special health care needs. To obtain this directory, see the information on organizations in the section on Resources for Children with Special Health Care Needs at the end of this booklet.

Support groups may also be available for families and siblings. Family-to-family support can often give insight into options for your child's care. Discussions may also help resolve the stress families experience and answer concerns that many parents have. Check with your health provider or local hospital to find out if there is a support group in your area. If not, you may be able to start one with the help of a social worker or nurse. Families may also find informal support through health education programs.

Recreation

Children with congenital heart disease can usually participate in all childhood activities. If your child has special restrictions, be sure to inform group leaders or coaches.

BEST COPY AVAILABLE

GLOSSARY

Arrhythmia - An irregular heart beat or a heart beat without rhythm.

Bacteremia - A condition in which bacteria enter the blood. This can cause damage to the heart if the bacteria lodge in heart valves or in the irregular surfaces of the heart.

Bacterial Endocarditis Prophylaxis - Antibiotic medication that kills bacteria; it is taken before dental or other surgical procedures. It prevents bacteria from lodging in valves and irregular surfaces in the heart.

Cyanosis - A bluish discoloration of the skin, resulting from too little oxygen in the blood.

Community-based care - Services available as close to home as possible; within the community as defined by the family; includes the local doctor, clinic, outreach specialty clinics, the public health nurse, the school, public and private agencies.

Culturally-sensitive - Care that is responsive to the values, beliefs, social norms, and behaviors of the individuals or populations being served; recognition of the values of different population groups. (From New England SERVE)

Developmental Delay - When children have not begun certain activities by the age that most children can perform the same activity. They may be slow to learn to talk, walk, feed and dress themselves, read, write, or other activities.

Echocardiogram - Ultrasound pictures of the internal structures of the heart and blood vessels.

Electrocardiogram (ECG) - A tracing of the electrical activity of the heart.

Family-Centered Care - Health care that recognizes the family as the constant in the child's life, and that is flexible, accessible, and responsive to family needs.

Family-Centered Health Care Team - A group of health care professionals who work together with the family to provide the best care for each child with special health care needs.

Individual Education Plan (IEP) - A plan for children receiving special education services; to meet the child's unique learning needs with a detailed plan.

Individual Family Service Plan (IFSP) - A plan to meet the unique needs of children with special needs ages 0 to 3 and their families; developed by a multidisciplinary team including the parents.

Multidisciplinary Team - A group of professionals from different fields who work together to give specialized services to the family.

Palpitations - A feeling of having an irregular or fast heart beat.

Prophylactic Antibiotics - Antibiotic medication that kills bacteria; it is taken before dental or other surgical procedures. It prevents bacteria from lodging in valves and irregular surfaces in the heart. This is also referred to as *bacterial endocarditis prophylaxis.*

Respiratory Infections - Illness caused by bacteria or viruses in the nose, throat, or lungs.

Subacute Bacterial Endocarditis - Inflammation of the inside of the heart caused by bacteria. Subacute means that symptoms may be minor and go unnoticed.

Syncope - Fainting or loss of consciousness.

RESOURCES

Children with Congenital Heart Disease

Organizations

American Heart Association of Minnesota (AHA)
4701 West 77th Street
Minneapolis, MN 55435
(612) 835-3300

The AHA of Minnesota has publications available from its national organization. Most of these publications are low cost or free. It also makes referrals to support groups.

Council on Cardiovascular Disease in the Young
American Heart Association National Center
7320 Greenville Avenue
Dallas, Texas 75231
(214) 373-6300

The national office of the AHA provides information to families and health professionals on specific heart conditions and recent research.

Parents for Heart
Children's Hospital of St. Paul
345 North Smith Avenue
St. Paul, MN 55102
(612) 220-6760

Parents for Heart
Southern Minnesota, Inc.
PO Box 5861
Rochester, MN 55903

Parents for Heart is an education and support group for parents of children with cardiovascular diseases. It holds meetings one evening each month. It also publishes a newsletter bimonthly, called *Heart to Heart* in the Twin Cities area and *Parents for Heart* in southern Minnesota. Call for more information.

BEST COPY AVAILABLE

The books listed here are available through the Minnesota public library system. Books that are not available in the local library can be borrowed from any other public library in Minnesota.

Cardiac Catheterization in Children. Pediatric Clinic University Hospital, MS Hershey Medical Center, Hershey, PA 17033. This is an 8-minute VHS video that shows the process of cardiac catheterization in children. It discusses preparation steps for the parents and child. The video is appropriate for parents or professionals and is available for purchase or for rent.

March of Dimes. 1988. *Public Health Information Sheet: Congenital Heart Defects.* 1-page general information sheet.

Moller, J., Neal, W., and Hoffman, W. 1988. *A Parent's Guide to Heart Disorders.* University of Minnesota Press, Minneapolis. 153 pages. This guide for parents was written by doctors at the University of Minnesota. It is the most comprehensive guide currently available for families of children with heart disorders. Chapters titles include a remarkable pump; the heart may be a problem; cardiac catheterization; congenital heart disease; acquired heart disease; cardiac arrhythmias; cardiac surgery; coping with a growing child; death, dying and grieving; and new horizons in prevention and research.

Singer, M. 1978. *It Can't Hurt Forever.* Harper & Row, New York, NY. 186 pages. This story, written for school-age children, is about an 11-year-old girl who has surgery for a heart defect.

Gillette, P. (Editor). 1990. Congenital Heart Disease. *Pediatric Clinics of North America.* 37(1): 1-231.

Greenwood, R. 1986. Five Heart Lesions to Find and Follow. *Contemporary Pediatrics.* Aug 86: 94-101.

Nadas, A. 1984. Update on Congenital Heart Disease. *Pediatric Clinics of North America.* Symposium on chronic disease in children. 31(1): 153-164.

Rosenthal, A. (Editor). 1984. Pediatric cardiology. *Pediatric Clinics of North America.* 31(6): 1159-1425.

Runton, N. 1988. Congenital Cardiac Anomalies: A Reference Guide for Nurses. *Journal of Cardiovascular Nursing.* 2(3): 56-70.

Santos, A., et al. 1986. Repair of Atrioventricular Septal Defects in Infancy. *Journal Thorac Cardiovasc Surgery.* 91: 505-510.

BEST COPY AVAILABLE

Specialty Medical Care for Children with Congenital Heart Disease

These medical facilities have pediatric cardiologists and offer specialty care for children with congenital heart disease.

The Children's Heart Clinic
2545 Chicago Avenue South
Minneapolis, MN 55404
(612) 871-4660

Children's Hospital of St. Paul
Children's Cardiology Clinic
St. Paul Heart and Lung Center
255 North Smith, Suite 203
St. Paul, MN 55102
(612) 220-6760

Mayo Clinic
Pediatric Cardiology
200 1st Street SW
Rochester, MN 55905
(507) 284-2911

Minneapolis Children's Medical Center
2525 Chicago Avenue South
Minneapolis, MN 55404
(612) 863-6111

Services for Children with Handicaps
Cardiac Clinics
Minnesota Department of Health
717 SE Delaware, PO Box Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (voice or toll free TDD)

University of Minnesota
Pediatric Cardiology Clinic
4-100 PWB
Minneapolis, MN 55455
(612) 626-6777

Please note:
This is a partial list of resources available in Minnesota. We do not endorse any specific organizations or publications. You will need to evaluate the quality of the services and determine if they fit your individual situation.

BEST COPY AVAILABLE

GENERAL RESOURCES

for Children with Special Health Care Needs

Organizations

Association for the Care of Children's Health (ACCH)
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 654-6549

ACCH publishes a variety of materials for families and professionals. It offers a newsletter, brochures and booklets, and videos to help families get the most out of the health care system. It also publishes the *Parent Resource Directory,* which contains the names and addresses of parents whose children have special health needs. Parents are listed by area and by their child's condition. The Minnesota chapter is coordinated by a parent. Call or write the national organization to for the current chapter address. Send for the ACCH publications catalog.

Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way N.E.
Seattle, WA 98115
(206) 523-8446

This is an organization of parents and professionals. It works to improve programs for people with severe handicaps. Call or write to the national organization for current information about the Minnesota chapter.

County Public Health Nursing Agencies
Minnesota Department of Health
Section of Public Health Nursing
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5468

Each county in Minnesota offers public health nursing services to residents of the county. Some counties offer respite care services or can help families locate respite care. The local agency may also help teach family members and babysitters about the care of the child with special health care needs. Contact your local county, or call the Minnesota Department of Health to locate your local office.

Courage Center
3915 Golden Valley Road
Golden Valley, MN 55422
(612) 588-0811

Courage Center offers services to children and adults with physical disabilities and speech, hearing and vision impairments and services are also available to family members. It offers adaptive driver education, a Communication Resource Center, camping experiences, a transitional residence program, support programs, physical and occupational therapy, and recreational and athletic activities. *Meeting Ground* is a free bimonthly newsletter written by and for families and health professionals. Call or write for a subscription.

The Early Intervention Project
Minnesota Departments of Health, Education and Human Services
Call your local school district for information.

The Early Intervention Project is a federally mandated program that operates through local interagency committees. Its purpose is to provide services for children from birth to three years of age who have special health care needs or developmental delays. Services may include respite care, public health nursing services, physical therapy, occupational therapy, speech and language therapy, early childhood special education, special equipment, family support activities, and training for parents.

Federation for Children with Special Needs
95 Berkeley Street
Boston, MA 02116
(617) 482-2915

The Federation for Children with Special Needs provides information and resources that focus on improving communication between families and health professionals. It also offers support for parents of children with special needs.

International Association for Medical Assistance to Travellers
IAMAT - USA Membership Office
417 Center Street
Lewiston, NY 14092

IAMAT is an organization that publishes a directory of English-speaking physicians around the world. Fees for visits are set at

low rates. It also offers health information for travelers. The membership and directory are free. Voluntary contributions are encouraged.

MedicAlert Foundation International
Turlock, CA 95381-1009
(800) ID-ALERT

MedicAlert makes identification necklaces and bracelets. The tags list medical information such as diagnosis, medications, and allergies. When someone purchases an ID, MedicAlert keeps a brief medical record on computer, which is updated yearly. Emergency medical personnel can call for more specific information than can be listed on the ID.

Metro Center for Independent Living (MCIL)
1619 Dayton Avenue, Suite 303
St. Paul, MN 55104
(612) 646-8342 (voice or TDD)
(612) 642-2507 (FAX)

MCIL offers transitional programs to promote independent living. Its Used Equipment Referral Service is a network between sellers, buyers, and donators of used equipment. It matches people who need equipment with those who have equipment available. Equipment includes wheelchairs, bathroom equipment, ramps, lifts, vehicles, hospital beds, walkers, prone standers, and more. Cosponsored by MCIL and United Cerebral Palsy of Minnesota.

Minnesota Department of Health
Genetics Unit
717 SE Delaware Street
Box 9441
Minneapolis, MN 55440
(612) 623-5269

Families can call the Genetics Unit to locate resources for genetic counseling for conditions that have a possible hereditary component.

Minnesota Department of Health
Services for Children with Handicaps (SCH)
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free voice or TDD)

SCH offers community-based clinics and services, health education and support programs, and health care financing to families of children with special health care needs. It also offers technical consultation to health professionals. SCH has district offices in Bemidji, Duluth, Fergus Falls, Mankato, Marshall, Minneapolis, Rochester, St. Cloud, and Virginia. Call for more information.

Minnesota State Council on Disability
145 Metro Square Building
7th Place and Jackson Street
St. Paul, MN 55101
(612) 296-6785 (voice or TTY)
(800) 652-9747 (Ask for Minnesota State Council on Disability)
This is an information and referral resource for people with disabilities who live in Minnesota.

National Center for Youth with Disabilities
Adolescent Health Program
University of Minnesota
Box 721 · UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-2825
(800) 333-6293
The center offers services to families, youth, and professionals to assist them in developing alternative service systems, which will allow adolescents and young adults to develop to their fullest capacity. It offers a National Resource Library and technical assistance by a network of professionals from many disciplines. The center also fosters the development of community-based services through a national network of federal and state information.

National Information Center for Handicapped Children and Youth (NICHCY)
P.O. Box 1492
Washington, D.C. 20013
(703) 893-6061
NICHCY is a national clearinghouse that provides information about many handicapping conditions. It also offers a list of parent groups throughout the United States and information regarding available services to disabled people.

National Rehabilitation Information Center
8455 Colesville Road
Suite 935
Silver Spring, MD 20910
(800) 346-2742

This organization offers a computer information service called ABLE DATA. Call for information.

PACER Center (Parent Advocacy Coalition for Educational Rights)
4826 Chicago Avenue South
Minneapolis, MN 55417-1055
(612) 827-2966 (voice & TDD)
(800) 53-PACER (toll-free)

PACER Center offers statewide workshops for families of handicapped children. The workshops inform parents of schools' rights and responsibilities to provide free appropriate education programs for children. Specific information is provided about Public Laws 94-142 and 99-457. Written materials are available in English, Spanish, and Hmong languages.

Pathfinder Resources
2324 University Avenue West, Suite 105
St. Paul, MN 55114
(612) 647-6905

Pathfinder works to improve the health and well-being of children with chronic conditions. It offers consultation and technical assistance in networking, education, public policy and financing, and publications.

Pilot Parents of Minnesota
201 Ordean Building
Duluth, MN 55802
(218) 726-4745

Pilot Parents is a parent network that matches families who have children with similar health or developmental conditions. Parents are trained to give information about services and educational programs, and can offer emotional support. Parents are available in most areas of Minnesota including northeastern, northwestern, central, and southeastern Minnesota. Pilot parents hope to have families available in southwestern Minnesota in 1990.

Siblings for Significant Change
105 East 22nd Street
Room 710
New York, NY 10010
(212) 420-0776

This Organization for siblings of disabled people. It offers information and referral services, counseling programs, and community education.

Sibling Information Network
Connecticut's University Affiliated Program
991 Main Street
New Hartford, Connecticut 06108

This is a clearinghouse of information for the siblings and families of disabled people. It offers quarterly newsletters with reviews, resource information, and discussions of family issues.

Wilderness Inquiry
1313 Fifth Street SE
Suite 327A
Minneapolis, MN 55414
(612) 379-3858

Wilderness Inquiry provides challenging wilderness experiences for physically disabled and nondisabled people. The camping trips require interdependence and cooperation. Experiences are available for families with children. Young adults over 18 years old may attend without family members. Some trips are available to teens 13 to 18 years old.

Books, Pamphlets, Videos, and Catalogs of Information

Adams, B. 1979. *Like It Is: Facts and Feelings about Handicaps from Kids Who Know.* Walker & Co., New York, NY. 96 pages. This book is written for school-age children and adolescents.

Aspen Publications. *Infants and Young Children.* 1600 Research Boulevard, Rockville, MD 20850. This journal is for parents and professionals who work with children. For more information phone (800) 638-8437.

Association for the Care of Children's Health, 1987. *Family-Centered Care for Children with Special Health Care Needs.* ACCH, Washington, DC. 74 pages. This book describes family-centered health care. Each chapter has a section that contains specific ideas to "make it happen." The final chapter includes checklists to help evaluate how well health providers are collaborating with families.

Association for the Care of Children's Health, 1988. *Seasons of Caring.* ACCH, Washington, DC. 40-minute videotape. Reveals the strengths and needs of families caring for children with special health care needs. Addresses many issues encountered by parents, teachers, social workers, school administrators, nurses, physicians, and others who care for children with special needs and their families. Another 38-minute video, *Family-Centered Care,* shows the experiences of several families around the country.

The Exceptional Parent. 605 Commonwealth Ave., Boston, MA 02215. This is a consumer magazine for parents of children with chronic conditions. The magazine is published eight times per year. It contains articles that provide practical information and emotional support for families.

Exley, H. (editor). 1984. *What It's Like to be Me.* Friendship Press, New York, NY. 127 pages. This book is written and illustrated entirely by disabled children. It's intended for school-age children and those in early adolescence.

Haig, B. and Moynihan, P. 1988. *Whole Parent/Whole Child: A Parent's Guide to Raising the Child with a Chronic Health Condition.* Diabetes Center, Minneapolis. How to help the child with a chronic health problem lead the fullest life possible. This book is written for families and health professionals who care for children with many different conditions.

Harnish, Y. and Leeser, I. 1984. *Patient Care Guides: Practical Information for Public Health Nurses.* National League of Nursing, New York, NY. 211 pages. This book has a section that contains patient care guides for children with chronic conditions. Some of the conditions included are mental retardation, myelodysplasia, neurological handicaps, muscular dystrophy, and cleft lip and palate.

Healy, A. and Lewis-Beck, J. 1987. *Guidelines for Families, Guidelines for Nurses, Guidelines for Physicians, Guidelines for Social Workers, Guidelines for Therapists.* University of Iowa Bookstore, Iowa City, IA 52242. Each of these booklets describes specific actions that can improve health care of children with chronic conditions.

Larson, G. (Editor), 1986. *Managing the School Age Child with a Chronic Health Condition.* Pathfinder and the School Nurse Organization of Minnesota, DCI Publishing. 335 pages. This book is a practical guide for schools, families, and organizations. A family may find it useful to review and discuss chapters about its child's condition with school personnel.

Mitchell, J. 1980. *See Me More Clearly: Career & Life Planning for Teens with Physical Disabilities.* Harcourt Brace Jovanovich, New York, NY. 284 pages. A comprehensive guide for youth with disabilities. Includes a section titled "Charting Your Course: Life Career Skills."

National Center for Education in Maternal and Child Health (NCEMCH). 1989. *Reaching Out: A Directory of National Organizations Related to Maternal and Child Health.* 38th & R Streets, NW, Washington, DC 20057. This resource guide lists organizations by specific disease or disability.

National Maternal and Child Health Clearinghouse (NMCHC) 1988. *Publications Catalog.* 38th & R Streets NW, Washington, DC 20057. 22 pages. Catalog of publications available through NMCHC. Most of these publication are free. One section lists publications about children with special health care needs.

Pediatrics for Parents. This newsletter is written to help parents understand pediatrics and health care issues so they can become informed, active participants in their child's health care. 10 issues per year. Write or phone for subscription information: Pediatrics for Parents, 358 Broadway, P.O. Box 1069. Bangor. MD 04401. Phone (207) 942-6212.

Randall-David, E. 1989. *Strategies for Working with Culturally Diverse Communities and Clients.* Association for the Care of Children's Health. Bethesda, MD. 96 pages. This guide is written to help professionals learn to provide culturally appropriate care to families and communities. It includes sections on assessing your own cultural heritage, learning about the community, working with culturally diverse groups, and using interpreters.

Routburg, M. 1986. *On Becoming a Special Parent: A Mini-Support Group in a Book.* Parent/Professional Publications, Box 59730, Chicago, IL 60645. Chapters on adjustment, equipment and toys, hospitals, respite, health care, medication, therapy, advocacy, individualized education program (IEP), and more.

St. Germaine, A. 1986. *Resource Manual for Physically Disabled Adolescents.* Gillette Hospital Interdependent Living Clinic, University of Minnesota Myelomeningocele Clinic. This manual contains Minnesota and national resources for youth. Topics include newsletters, funding sources, camps and special programs, social and recreational programs, counseling, transportation, residences, and transitional programs.

Segal, M. 1988. *In Time and With Love: Caring for the Special Needs Baby.* Newmarket Press, New York, NY. 192 pages. For families and caregivers of preterm and handicapped children ages birth to 3 years. Information is included about coping; nursing, feeding, and dressing; social skills; games and activities; discipline; and decision making.

United Cerebral Palsy of Minnesota. *Health Care Coverage and Your Disabled Child: A Guide for Parents.* 31 pages. This booklet answers many questions parents might have about health care coverage for their children. It describes types of insurances, HMOs, and alternative ways to finance health care.

Health Care Financing

There are many types of health care financing available to families with children with special health care needs. Each plan covers different services. Eligibility requirements also differ. Listed are some of the most common payment systems. Contact your local county human services office or the providing agency to find out if you are eligible for any of these.

Children's Health Plan (CHP)
444 Lafayette Road
St. Paul, MN 55155-3829
(612) 297-3862
(800) 652-9747 (Ask for Children's Health Plan)

The Children's Health Plan offers health care insurance for under insured or uninsured children 1 through 8 years old. After January 1, 1991, the plan will be available to children 1 through 17 years old. Coverage costs $25 per year, per child. Eligibility is based on income and family size.

Medical Assistance Program (MA)
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
(612) 296-3386
(800) 652-9747 (Ask for Medical Assistance)

Medical Assistance offers health care financing for families. Eligibility is based on income and family size. Children with chronic health conditions may qualify for full Medical Assistance benefits based on their income and assets alone under a waiver. For information, call your county human services office or the state office listed here. Local county human service agencies may also have funds under Title XX Social Service Programming, Family Subsidy, or Permanency Planning Grant.

Waivers

Waivers provide medical assistance benefits to children counting only the child's income and assets to determine eligibility. Expenses covered vary with each type of waiver.

Children's Home Care Option (TEFRA 134)
Medical Assistance is offered under the Children's Home Care Option or TEFRA. Children must be certified as disabled by the Social Security Administration or the State Medical Review

Team. Children are cared for at home. Eligible children have all regular medical assistance expenses covered.

Community Alternative Care (CAC)
The program offers home and community care services for chronically-ill children. Children must be residents of a hospital or be likely to need inpatient hospital care. Children are cared for at home. The program covers expenses for care that cost less than it would at an institution covered by Medical Assistance.

Community Alternatives for Disabled Individuals (CADI)
This program covers applicants to or residents of nursing care facilities. The person must be certified as disabled. Children are cared for at home. The program offers home and community care services for disabled individuals under age 65. It covers expenses for care that cost less than they would at an institution covered by Medical Assistance.

Home and Community Based Waiver for Persons with Mental Retardation or Related Conditions (MR/RC)
Individuals diagnosed with mental retardation or a related condition of any age are eligible. The person is cared for at home. This waiver covers expenses for care that cost less than it would at an institution covered by Medical Assistance.

Services for Children with Handicaps (SCH)

Minnesota Department of Health
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free, voice or TDD)

Services for Children with Handicaps offers financial help for health care to children with special health care needs. Eligibility is based on income and number of family members. SCH serves children from birth to age 21 years. Services for Children with Handicaps has district offices in Bemidji, Fergus Falls, Virginia, Duluth, Marshall, St. Cloud, Minneapolis, Mankato, and Rochester.

Notes

40 BEST COPY AVAILABLE

Minnesota Department of Health
717 Delaware St. S.E.
P.O. Box 9441
Minneapolis, MN 55440